

**Department of Health and Human Services  
National Institute of Environmental Health Sciences  
National Cancer Institute**

**Minutes of the Research Translation, Dissemination, and Policy Implications  
Subcommittee of the Interagency Breast Cancer and Environmental Research  
Coordinating Committee**

**August 17, 2011**

The Research Translation, Dissemination, and Policy Implications (RTDPI) Subcommittee of the Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERCC) was convened for a meeting on August 17, 2011 at 1:00 PM EST via conference call. The Chair of the subcommittee was Jeanne Rizzo, R.N. of the Breast Cancer Fund.

**Subcommittee Members Present**

Beverly Canin  
Ysabel Duron  
Karen Miller  
Marcus Plescia, M.D., M.P.H.  
Jeanne Rizzo, R.N.  
Shelia Zahm, Ph.D.

**NIH Staff Present**

Jennifer Collins, M.R. (NIEHS)  
Christie Kaefer, M.B.A., R.D. (NCI)  
Liam O'Fallon, M.A. (NIEHS)

**Guests**

Connie Engel, Ph.D. (Breast Cancer Fund)  
Melissa Palmer, M.P.H. (CDC)

**I. BACKGROUND**

The Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERCC) is a congressionally mandated body established by the National Institute of Environmental Health Sciences (NIEHS), in collaboration with the National Cancer Institute (NCI). This Committee is comprised of 19 voting members, including representatives of Federal

agencies; non-federal scientists, physicians, and other health professionals from clinical, basic, and public health sciences; and advocates for individuals with breast cancer.

The Committee's primary mission is to facilitate the efficient and effective exchange of information on breast cancer research activities among the member agencies, and to advise the NIH and other Federal agencies in the solicitation of proposals for collaborative, multidisciplinary research, including proposals to further evaluate environmental and genomic factors that may be related to the etiology of breast cancer. The Committee serves as a forum and assists in increasing public understanding of the member agencies' activities, programs, policies, and research, and in bringing important matters of interest forward for discussion.

The objectives of the RTDPI Subcommittee of the IBCERCC are integrated and dependent on the objectives and activities of the other Subcommittees of the IBCERCC and include the following: to identify successful models as well as gaps in research translation and dissemination, to make recommendations to improve both with an emphasis on breast cancer and the environment; to make policy recommendations to that end; to address areas in which the scientific evidence on breast cancer and the environment supports precautionary public health policy; and to identify methods to expand public participation in the research translation and dissemination processes to more effectively involve patient advocacy and community organizations, environmental health, environmental justice as well as practitioners in public health and health care delivery.

The seventh meeting (conference call) of the RTDPI Subcommittee took place on August 17, 2011. During this meeting, Ysabel Duron, a new IBCERCC member, was introduced to the RTDPI Subcommittee, past meeting minutes were discussed, along with the Subcommittee's draft chapters for the IBCERCC report. The minutes from the May and June meetings were reviewed and approved with corrections.

## **II. DISCUSSION**

### ***Introduction***

Jeanne Rizzo introduced Ysabel Duron, a new IBCERCC member, who is joining the RTDPI Subcommittee. Ysabel is an award-winning journalist with more than 30 years in television broadcasting. Ysabel is also a breast cancer survivor and founder of Latinas Contra Cancer (LCC). LCC was founded in California but works nationwide to address the void in culturally and linguistically sensitive programs that meet the health care needs of Latinos around issues of cancer.

## ***Draft IBCERCC Report***

Jeanne informed the RTDPI Subcommittee that Connie Engel now has a contract to help with the RTDPI chapters for the IBCERCC report. Jenny Collins has been obtaining information from NIH about formatting requirements for the IBCERCC report. So far, it appears that the only set requirements relate to any recommendations that will be made by the IBCERCC to the Secretary, HHS. Beverly would like to ensure there is some continuum between the RTDPI chapters. Connie suggested it would be easiest to create bridges between the chapters once the content for all three RTDPI chapters has been determined. Additionally, Jeanne suggested that the introduction section will also help connect the chapters. At the September IBCERCC meeting in North Carolina, the Subcommittee will learn more about the proposed content for the other Subcommittees' chapters; however, Jenny will circulate information that she has, such as a table from the State-of-the-Science Subcommittee with recommendations that relate to dissemination.

Ysabel recommended that there should be some discussion in the RTDPI section of the report that address research gaps in communities of color. Jeanne indicated this has been brought up in previous meetings by all three Subcommittees; the RTDPI Subcommittee has discussed this in terms of the development of culturally appropriate outreach materials. Jenny will try to learn more about how this will be dealt with by the other Subcommittees, but indicated it would be helpful if RTDPI members could provide key search terms relevant to the research portfolio. Connie offered to compile suggested search terms and send to Jenny.

Melissa raised a concern about overlap between the IBCERCC Subcommittees and asked how the IBCERCC should capture that to maximize recommendations. For example, what if the recommendations include something related to policy or system changes (e.g., communication processes between Federal agencies related to newly issued reports, etc.)? Jeanne indicated it will be up to the full Committee to decide once all the recommendations can be reviewed and determine how the recommendations will be made to the Secretary, HHS.

Regarding the Federal research portfolio on breast cancer research, Jenny said they are currently trying to categorize all breast cancer grants using the Common Scientific Outline. One category is "education," so for example, they could sort the grants by "education" and "etiology." The portfolio analysis could be used to identify gaps and barriers to interventions. Karen Miller also thought timing of exposures and their relationship to disease outcome might be important as well. It currently is a challenge in terms of public health, communication, and lifestyle choices because of the long lag time between exposures and disease onset. Another issue discussed that has been raised in the Research Process Subcommittee and which has been captured in Team 1's work, is the infrequent lack of involvement of community members in the peer review process.

Jeanne reviewed who are the primary “owners” of each RTDPI chapter:

Team 1 (Research Translation): Beverly, Karen, Ronda

Team 2 (Policy Implications): Jeanne, Shelia, Marcus

Team 3 (Research Dissemination & Communication Issues): Jeanne asked Isabel if she would join this team and work with Marcus (and Galen Cole at CDC), Liam O’Fallon, and Connie.

Although the above individuals “own” various sections of the report, others on the RTDPI Subcommittee will still contribute to each section.

### ***Team 1 Update***

Team 1 asked for input on whether they should structure the discussion of best practices related to research translation by selecting a few specific models (such as the Breast Cancer and Environment Research Program, California Breast Cancer Research Program, the Pediatric Environmental Health Specialty Units, and the Silent Spring Institute) or more broadly identify strengths in a variety of existing programs? Karen and Beverly indicated they preferred the second option. Jeanne asked whether they thought the “best practices” would be applicable in all situations. Beverly thought they could create an ideal model and indicate which elements would or would not work in certain situations. Shelia thinks there are different best practice models, such as models relevant to basic science and models for use when there are immediate public health or clinical practice implications. Karen agreed.

Shelia thought it might be overly ambitious for the Subcommittee to create an ideal model however, they could suggest that Federal agencies give additional consideration to this issue.

Jeanne asked if there are any interagency communication models. Liam said NIEHS is at the forefront in working with community partners (not as research subjects). Other agencies, such as EPA, have different models. EPA’s Administrator, Lisa Jackson, and its Senior Advisor for Environmental Justice, Lisa Garcia, have remarkable lines of communication for environmental justice issues. There is a growing need for interagency discussions. Examples of other relevant Federal efforts include those by ATSDR, CDC, and the Interagency Environmental Justice Working Group. Connie offered to reach out to Lisa Garcia for further discussion. Liam also mentioned he interacts with Sharunda Buchanan, M.S., Ph.D., at CDC (Director, Division of Emergency and Environmental Health Services, National Center for Environmental Health) and could follow up with her.

The RTDPI members were reminded that the primary target audience is the HHS Secretary, but the report can go to other audiences, such as Congress and their constituents. Ysabel recommended that each chapter include real stories to connect faces to the issues so the report becomes of interest to the public so they will help push for change. Connie mentioned there are

multiple ways the IBCERCC could present its report. For example, the Breast Cancer Fund prepares a lengthy report for Congress, but accompanies it with blogs and other materials that are short and more interesting ways of getting the word out to a variety of audiences. Shelia liked the idea of “side stories” for audiences such as the media. Christie will send a link to RTDPI members for the NCI Bypass Budget as an example of a relatively short document produced by NCI that targets government leaders and includes the use of side stories featuring cancer research.

Beverly thought the IBCERCC recommendations would come from a lot of different sources and would not necessarily be wedded to specific chapters or Subcommittees.

### ***Team 3 Update***

The communications section of the report is not well developed to date. Jeanne focused the group’s attention to what Galen generated ([Considerations for Scientists Communicating in a Media Intensive Era.doc](#)). Ysabel asked whether there was already a framework for writing this section noting that she hasn’t seen the document Galen prepared. Jeanne explained that the communications section has not been developed and the group needed to determine what should be included. Jeanne thought it would be good to have a toolkit as an addendum. Connie said the group needs to get clear assignments in place so that they can have a draft by the September meeting. Melissa (representing Marcus on the call) will try and find out if Marcus and/or Galen are available tomorrow to meet by phone to start working on this section.

The group agreed that advocates currently seem to do a lot of the communications work after the research is published. How can there be better integration? Jeanne informed the group that there was a very useful discussion at the recent NIEHS strategic planning meeting regarding communications research. Liam noted that the report from this discussion is available on the NIEHS web: <http://www.niehs.nih.gov/about/od/strategicplan/stakeholder-community-workshop/reports/priority4.pdf>. IBCERCC recommendations could state the need for communications research – not just the need to communicate research findings. Liam asked the group to clarify what level the RTDPI Subcommittee will focus on and noted that there are communication issues pertinent to the research level as well as individual Institute and Agency level communications strategy, and interagency communications. Connie, Ysabel, and Liam will meet at 9:00 EDT tomorrow using the IBCERCC conference call line and hopefully Galen or Marcus will also be available. Melissa will stress that it is time sensitive.

## *Team 2 Update*

There was no new progress to present. Jeanne asked for discussion regarding the format of this section. Shelia noted that we know that policy issues are important. They have drafted text on Right to Know and precautionary principle, etc. Other reports have covered this topic. Should this section focus on the policy matters that will be coming out of this report? If this is the case, the RTDPI Subcommittee needs to see what issues the other Subcommittees raise. This needs to be clarified to determine what the assignments are moving forward.

Jeanne went back the definition of policy implications presented in the “RTDPI full section intro, team 1 narrative.doc” sent by email prior to the call.

“Policy implications include policies that follow directly and indirectly from the translation and dissemination of a body of research, and that act as the means for bringing about measurable changes in breast cancer incidence, morbidity and mortality. Research process and results must be tied to programs at the federal, state, and local level to communicate results and to implement regulations or other actions to effectively prevent, diagnose, or treat breast cancer. Such policies are directly connected to research. Effective policies emerge from the recognition that prevention of disease is often best achieved by addressing systemic and population-based issues, and such policies provide agencies with the means, methods and jurisdiction to address these system-level concerns. (Note: the above definition was drafted from ideas that emerged in the May meeting in N. Carolina, but the subcommittee needs to review.)”

Jeanne asked when we talk about policy, what are we including? Are we talking about regulatory and/or public health policy (how medical care is delivered, etc.)? Beverly thought this can be approached in the same way that the translation group addressed. There needs to be good examples available.

Connie asked what term we are defining. Jeanne suggested it will depend on the policy implications of the report, e.g., what policies are needed as a result of what we see in the State-of-the-Science and Research Process sections of the report.

Shelia proposed that each section could present both recommendations AND policy implications.

The group discussed the shifting the burden-of-proof (using first responders and cancer as the example). Jeanne brought up the Camp Lejeune study. Maybe this could be a case study of the precautionary principle not in action.

Jeanne asked if we want to talk about how the various Federal agencies inform each other? EPA conducts research and is also regulatory. How do the agencies communicate with each other on

issues? The group discussed the endocrine disrupting (ED) legislation as an example. If NIEHS found a chemical to have a certain level of ED activity that it would then be regulated.

Liam asked if it would be appropriate to examine how (at a more local level) are communities engaged with researcher to illicit policy change. Or is this too granular? Karen stated that if you are working with an Environmental Health Sciences (EHS) Core Center this is easier. If there is no EHS Core Center, it is extremely difficult. There is a great divide between the two situations. Jeanne commented that NIEHS at the end of the day does not take a position on the endocrine disruptor bill. It would force NIEHS into a regulatory role which is outside its primary mandate. Do we want NIEHS to weigh in on every policy piece? What do we want out of this? Shelia said that, as an NCI scientist, we don't want to be regulatory; we want to do the research.

Jeanne asked what kind of science do we need to do to create a public health or policy intervention. The regulators are missing this piece. Do we want to encourage an interagency collaborative process that would speak to this issue – getting the regulators all of the pieces that would be needed to result in action? The group could use a few examples to illustrate (such as Shelia's smoking example). Liam said he had a few examples that he can send around.

Connie suggested that it seems like we do need to revise the definition of policy implications based on today's discussion. Sheila and Marcus will work on this.

#### **Action Items, assignments, and due dates:**

- Jeanne reviewed what she had on the annotated agenda sent today. Connie/Shelia/Jeanne will reach out to Marcus to work on the policy implications sections.
- Next call is September 13. By that date – ideally we would have:
  - Full draft of Translation Chapter ( 7 pages) + appendices
  - Full draft of Dissemination sections of Chapter 2 ( 4 pages) + appendices
  - Full draft of Communications sections of Chapter 2 ( 4 pages) + example of tool kit
  - Full draft of Policy Implications Chapter ( 7 pages) + appendices

**NOTE: Deadline for final drafts COB September 22, 2011 (latest time zone).**

- Jenny will send materials from the other two IBCERCC Subcommittees.
- All RTDPI members should send Jenny key search terms of interest to the Subcommittee's work so she can do some data mining in the Federal portfolio for breast cancer research.
- All should review NCI Bypass Budget as possible report format (including side stories).

### **III. ADJOURNMENT**

The meeting adjourned at 4:00 on August 17, 2011.

## **CERTIFICATION**

/Jeanne Rizzo/

Jeanne Rizzo, RN

Chairperson

Research Translation, Dissemination, and Policy Implications Subcommittee

Interagency Breast Cancer & Environmental Research Coordinating Committee

/Gwen W. Collman/

Gwen W. Collman, PhD

Executive Secretary

Research Process Subcommittee

Interagency Breast Cancer & Environmental Research Coordinating Committee

Proper signatures

Treat as signed, § 1.4(d)(2)